



Evaluation of First 5 California's Comprehensive Approaches to Raising Educational Standards (CARES) Program Research Protocol

County Responsibilities in Ensuring Participant Data Confidentiality

In order to minimize the risk of inadvertent unauthorized disclosure of Comprehensive Approaches to Raising Educational Standards (CARES) participant's personal data, all CARES partners, including First 5 California, county commissions, contracted program staff (including Andrew J. Wong, Inc. {AJWI}), grantees, evaluators and/or their agents must employ the following procedures:

1. Limited access to data.

County commissions and their agents shall set forth in their contracts specific limits on the information they release. They will limit sharing information to:

- a. Information necessary to develop and provide services on behalf of the participant;
- b. The need to evaluate the efficiency and effectiveness of agent services; and
- c. The need to evaluate the success of the CARES program in achieving First 5 California and county commission objectives as stated in their strategic plans.

By law, county commissions' agent staff may be required to release confidential information about a participant without specific authorization only if the staff has reason to believe that the participant is a danger to himself or herself or to others or if the participant is an alleged victim or perpetrator of child, elder or dependent abuse.

2. Computer access will be protected.

County commissions have the option to use the CARES Microsoft Access database that is password protected. The password ensures that the data

is secure even on computers where multiple staff have access. AJWI provides the password to a county commission designee and the designee assigns permission to the person inputting data.

County commissions that choose not to use the CARES database must create their own data input access regulations consistent with First 5 California protocol which requires counties to keep CARES data on a single computer with limited, password protected access.

3. Research records will be protected:

CARES partners will acquire and store all confidential participant information in a manner that safeguards the privacy rights of the participant. Each county commission is responsible for carefully monitoring the data collection, storage and reporting of confidential participant information maintained in their database. The county commissions will place the following information in a personal paper or electronic file folder:

- a. The original, signed copy of the participant's Consent Authorization form, and
- b. Any other information regarding the participant

County commissions will store this information in a location accessible only to authorized staff who have executed the appropriate confidentiality agreement as described above and who can document a direct, specific, and time-limited need for the confidential information to which they request access. The county commissions will only share the participant's confidential information with authorized First 5 California staff, county commission staff and AJWI representatives if the participant provides informed consent. First 5 California or county commissions will authorize an administrator to oversee all participant records.

4. County staff will assure that:

- a) Oral communication between county commission or agent staff and the participant cannot be overheard in the interview setting by unauthorized staff, other program participants or visitors.
- b) Written communications pertaining to a participant's case is not accessible to unauthorized staff, other program participants or visitors.
- c) County commission staff or agents ask the participant about the comfort level of the interview setting as related to the participant's confidentiality. County commission staff or authorized agents will accommodate a request for a more private interview setting.

- d) Data will not be reused or provided to any persons outside of the research team, except as noted above, to program and agent staff that provide services.
- e) Data will be transported only through secure means.
- f) Data will not be accessible to the public via the Internet.
- g) Data will not be left on unattended or unsecured laptop computers.
- h) Data will be destroyed when consent authorization forms are no longer valid.

5. Other Considerations

First 5 California, county commissions and AJWI will not publish information that could be used to identify an individual subject. CARES data analyses will be generated using a dataset with all individually identifiable information removed. Aggregated data will be used in all reports.

In addition to the safeguards above, all parties who participate in data sharing with First 5 California, county commissions, county agents, and evaluators are required to comply with all applicable laws, regulations grant agreements, and contractual conditions pertaining to the receipt of funds from the state and/or county commissions. **To facilitate this requirement, each agent is required to develop a written, internal confidentiality policy that mirrors and supports that of the Commission, Federal, State, and local laws and regulations.**

Any violation of this Protocol that involves inappropriate and/or unauthorized release of a participant's confidential information may be grounds for contract termination, and may expose the violator to civil and/or criminal penalties.

6. Staff Training

AJWI will provide county commission and authorized agent staff training on an as needed basis. AJWI will remind counties of security and confidentiality protocols and county commissions' responsibilities in maintaining them during the training. First 5 California will update county commissions on changes to data confidentiality protocol, as changes occur, or as needed.

7. Informed Consent

County commissions or their agents will use the following procedures to obtain and document informed consent from participants.

a. Administration of Authorization

All participants must sign the Authorization form before AJWI can extract data from the CARES database or use other CARES data to conduct analysis. First 5 California, county commissions and agents are responsible for notifying participants of confidentiality protocols and ensuring that they are educated about their rights.

In every case, the county commission or agent must keep the original signed Authorization form. The participant may withdraw authorization at any time. The “*Request to Cease Participation in the CARES Program Evaluation*” form is available from Gretchen Williams at First 5 California at (916) 263-1051 or gwilliams@ccfc.ca.gov.

Authorization will be effective until 10 years after the date the form is signed.

b. Understanding the Authorization

Program administrators will provide a hard copy of the Authorization consent form in English or Spanish. If the participant does not speak the languages spoken by staff, or cannot adequately read in the languages in which the Authorization form is available, then it is the responsibility of the organization collecting the information, to provide an interpreter, or to read the form to the participant, and to sufficiently explain any difficult wording. The responsible staff person will make sure he or she provides orientation in a language that the participant can fully understand. The responsible staff person will respond fully, appropriately, and in a timely manner to the questions and concerns of the participant related to the forms or the confidentiality policy and procedures.

c. Removal of Authorization

The participant may revoke authorization at any time by completing a “*Request to Cease Participation in the CARES Program Evaluation*” form and submitting the completed form to the county commission. Participants may not revoke First 5 California, AJWI, and county commission or agent actions prior to the revocation of the authorization. First 5 California, county commissions, AJWI, and/or agents will remove from the evaluation all confidential and/or

identifying information on participants who have revoked their authorization in a timely manner.

If a participant does not wish to have information included in the CARES program evaluation, it will not impact participation in the CARES program.

Required Federal Policy Statement: Prohibition on Re-disclosing Confidential Information Concerning Participants Receiving Services:

"This notice accompanies a disclosure of confidential information concerning a participant of services funded by the county commission. This information has been disclosed to you from records protected by Federal confidentiality rules 45 CFR Part 46, 42 CFR Part 2, or 45 CFR Parts 160 and 164 (HIPAA Regs.) These Federal rules prohibit you from making any further disclosure of this confidential information unless further disclosure is expressly permitted by the written authorization to release the information of the person to whom it pertains or as otherwise permitted by these regulations. A general authorization for the release of medical or other confidential information is NOT sufficient for this purpose. The Federal rules specifically restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse consumer."

d. Participant Rights and Responsibilities:

- I. Only the participants may approve access to or release of confidential information and records related to the participant.
- II. Participants must be properly informed of their rights and responsibilities. This includes informing the participant about the sharing of confidential participant information among agents and commission partners, and how this information will be used and secured.
- III. A participant who agrees on his or her own behalf to participate in services funded by county commissions will be asked to provide personal and uniquely identifying information for the CARES evaluation. Participants must indicate, through the Authorization form, their understanding and willingness to participate in this data-sharing effort.